



# **Direct Support Person's Training Program Children's Module**



## **INTRODUCTION**

This Children's Appendix Module contains information for Direct Support Persons (DSPs) who provide direct care to children and young adults under the age of eighteen, many of whom are now receiving home and community based services through the Division of DD's Medicaid Home and Community-Based Service waiver program. The service delivery methods are participant and family directed. Direct care providers can be employees of the participant, or employed through community agencies. This Children Appendix is designed to be a resource for both types of providers. The topics covered in this module include:

- Providing supports to children with autism, cerebral palsy, mental retardation and epilepsy
- Developmental Milestones
- Early Intervention and Special Education
- Child Abuse and Neglect Reporting Information Developmental Delay in Children
- Basic Communication Principles
- How Children Grieve
- Guardianship vs. Parental Rights
- Types of Guardianship for Children Under 18
- DCFS Guardianships
- Separation Anxiety in Children with Developmental Disabilities
- Children's Service Planning
- Finding Resources for Children

## Introduction to Developmental Disabilities

Developmental disabilities are a diverse group of severe chronic conditions that are due to mental and/or physical impairments. Children with developmental disabilities have problems with major life activities such as language, mobility, learning, self-help, and independent living. The following information provides information and guidelines concerning on the different categories of developmental disabilities and how you can provide supports to supporting children who have these disabilities.

### Cerebral Palsy (CP)

**Cerebral palsy** is a condition that affects thousands of babies and children each year. The word **cerebral** means having to do with the brain. The word **palsy** means a weakness or problem in the way a person moves or positions his or her body.

A child with CP has trouble controlling the muscles of the body. Normally, the brain tells the rest of the body exactly what to do and when to do it. However, because CP affects the brain, depending on what part of the brain is affected, a child might not be able to walk, talk, eat, or play the way most children do.

Some children with CP use wheelchairs and others walk with the help of crutches or braces. In some cases, a child's speech may be affected or the person might not be able to speak at all.

### Types of Cerebral Palsy

There are three types of cerebral palsy: **spastic** (pronounced: spass-tick), **athetoid** (pronounced: **ath**-uh-toid), and **ataxic** (pronounced: ay-**tak**-sick). The most common type of CP is spastic. A child with spastic CP can't relax his or her muscles or the muscles may be stiff.

Athetoid CP affects a child's ability to control the muscles of the body. This means that the arms or legs that are affected by athetoid CP may flutter and move suddenly. A child with ataxic CP has problems with balance and coordination.

A child with CP can have a mild case or a more severe case — it really depends on how much of the brain is affected and which parts of the body that section of the brain controls. If both arms and both legs are affected, a child might need to use a wheelchair. If only the legs are affected, a child might walk in an unsteady way or have to wear braces or use crutches. If the part of the brain that controls speech is affected, a child with CP might have trouble talking clearly. Another child with CP might not be able to speak at all.



For some babies, injuries to the brain during pregnancy or soon after birth may cause CP. Children most at risk of developing CP are small, premature babies (babies who are born many weeks before they were supposed to be born) and babies who need to be on a ventilator (a machine to help with breathing) for several weeks or longer. But for most children with CP, the problem in the brain occurs before birth. Often, doctors don't know why.

Source: [http://kidshealth.org/kid/health\\_problems/brain/cerebral\\_palsy.html](http://kidshealth.org/kid/health_problems/brain/cerebral_palsy.html)

### **Children with Autism Spectrum Disorder**

Autism spectrum disorders (ASDs) are a group of developmental disabilities defined by significant impairments in social interaction and communication and the presence of unusual behaviors and interests. Children with ASDs also have unusual ways of learning, paying attention, or reacting to different sensations. The thinking and learning abilities of people with ASDs can vary – from gifted to severely challenged. ASD begins before the age of 3 and lasts throughout a person's life. It occurs in all racial, ethnic, and socioeconomic groups and is four times more likely to occur in boys than girls.

In February 2007, the Centers for Disease Control and Prevention issued its autism prevalence report (<http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5601a1.htm>). The report, which looked at a sample of 8 year olds in 2000 and 2002, concluded that the prevalence of autism had risen to one (1) in every 150 American children, and almost one (1) in 94 boys. The issuance of this report caused a media uproar, but the news was not a surprise to ASA or to the 1.5 million Americans living with the effects of autism spectrum disorder. Nonetheless, the spotlight shown on autism as a result of the prevalence increase opens opportunities for the nation to consider how to serve these families facing a lifetime of supports for their children.

ASDs can often be detected as early as 18 months. Research shows that early intervention can greatly improve a child's development. Autism is treatable. Children do not "outgrow" autism, but studies show that early diagnosis and intervention lead to significantly improved outcomes.

- Here are some characteristics the children you support may demonstrate: Lack of or delay in spoken language
- Repetitive use of language and/or motor mannerisms (e.g., hand-flapping, twirling objects)
- Little or no eye contact
- Lack of interest in peer relationships
- Lack of spontaneous or make-believe play
- Persistent fixation on parts of objects

Content source: National Center on Birth Defects and Developmental Disabilities

Sources: U.S. Department of Health and Human Services Centers for Disease Control and Prevention  
Autism Society of America

## **Children with Intellectual Disability**

Young children with intellectual disability may need assistance developing certain basic skills (e.g., motor skills, speech and language skills). Children with intellectual disability often can participate in many activities (e.g., sports, dance, music, art) with other children their age who do not have developmental disabilities. Their abilities to participate in these activities depend on their overall physical condition, including any condition that may have caused their intellectual disability.

It is important that children with intellectual disability are treated kindly and fairly. They may realize that they are behind other children their age in development and academics. In some cases, they may be bullied. Some of these children suffer from anxiety and frustration and some may act out in order to gain attention. Children with intellectual disability need encouragement and support to prevent or overcome these potential obstacles.

These children are eligible for early intervention services. These services include an Individualized Family Services Plan (IFSP). This plan evaluates the unique needs and goals for each child and devises methods to address them.

Early intervention services frequently focus on adaptive skills. These are the skills that allow an individual to live, work and play in his or her community. They include communication skills, self-care skills (e.g., dressing, bathing, toilet training), health and safety lessons, home skills (e.g., making the bed, cleaning the bedroom, setting the table) and social skills (e.g., manners, rules of conversation, group structure and playing games).

Once children with intellectual disability reach school-age, an Individualized Education Plan (IEP) replaces the IFSP. Like the IFSP, the IEP evaluates and addresses the unique needs and goals of a child. However, the plan is now more geared toward academics and school. Children with intellectual disability require a special setting, including individual attention and support. However, many children with mild intellectual disability may attend regular classes with other children their age, although they still require personal assistance from a teacher or aide, both in and out of the classroom. The education of children with intellectual disability focuses on lifelong vocational pursuits. A particular interest or talent may be honed, with special vocational training or exposure to the job setting. For example, a child with an interest in cars may be educated with a strong focus towards machines and mechanics.

There are a number of steps parents, caretakers and teachers of children with intellectual disability can take to help the child. It is important to encourage independence, including teaching adaptive skills whenever possible. The presentation of tasks and information needs to be concrete and clear. Breaking tasks and new information into smaller steps and facts and giving immediate feedback tends to help these children learn. Appropriate chores, with special attention to the child's age,

attention span and abilities, can make the child feel productive and independent. Socialization (e.g., scouts, recreational center activities, sports) can help build social skills and allow the child to have fun with other children of similar age. The child's strengths and interests can be emphasized both in the classroom and at home.

Source: <http://yourtotalhealth.ivillage.com/mental-retardation>

### **Children with Epilepsy:**

Epilepsy is a condition that from time to time produces brief disturbances in the normal electrical functions of the brain. When someone has epilepsy, this normal pattern may be interrupted by intermittent bursts of electrical energy that are much more intense than usual. They may affect a child's consciousness, bodily movements or sensations for a short time. These physical changes are called epileptic seizures. That is why epilepsy is sometimes called a seizure disorder.



Conditions in the brain that produce these episodes may have been present since birth, or they may develop later in life due to injury, infections, structural abnormalities in the brain, exposure to toxic agents, or for reasons that are still not well understood. Many illnesses or severe injuries can affect the brain enough to produce a single seizure. When seizures continue to occur for unknown reasons or because of an underlying problem that cannot be corrected, the condition is known as epilepsy.

The Epilepsy Foundation offers this advice to individuals who provide supports to children with epilepsy/seizure disorders:

- A child with a seizure disorder should always get medicine on time.
- It is nobody's fault if a child has a seizure. It is not the child's fault and it is not yours.
- Most seizures are not emergencies and do not require emergency care.
- Talk things over with parents beforehand and know exactly how they want you to handle a seizure should one occur.
- First aid for seizures is mostly keeping the child safe until the seizure ends naturally.
- If a child has a convulsion, turn the child on one side to prevent choking.
- Having a seizure is upsetting and embarrassing to the child. Children need comfort and kindness afterwards.

Call for emergency assistance if the seizure goes on for more than five minutes, if another seizure starts, or if the child doesn't wake up or breathe properly afterwards.

### Children with Autism

Autism spectrum disorders (ASDs) are a group of developmental disabilities defined by significant impairments in social interaction and communication and the presence of unusual behaviors and interests. Children with ASDs also have unusual ways of learning, paying attention, or reacting to different sensations. The thinking and learning abilities of people with ASDs can vary – from gifted to severely challenged. ASD begins before the age of 3 and lasts throughout a person's life. It occurs in all racial, ethnic, and socioeconomic groups and is four times more likely to occur in boys than girls.



ASDs can often be detected as early as 18 months. Research shows that early intervention can greatly improve a child's development.

### Fetal Alcohol Information

Prenatal exposure to alcohol can cause a range of disorders, known as fetal alcohol spectrum disorders (FASDs). One of the most severe effects of drinking during pregnancy is fetal alcohol syndrome (FAS). FAS is one of the leading known preventable causes of intellectual disability and birth defects. If a woman drinks alcohol during her pregnancy, her baby can be born with FAS, a lifelong condition that causes physical and mental disabilities. FAS is characterized by abnormal facial features, growth deficiencies, and central nervous system (CNS) problems. Children with FAS might have problems with learning, memory, attention span, communication, vision, hearing, or a combination of these. These problems often lead to difficulties in school and problems getting along with others. FAS is a permanent condition. It affects every aspect of a person's life and the lives of his or her family.

**All FASDs are 100% preventable—if a woman does not drink alcohol while she is pregnant.**

### What are the characteristics of children with FAS and other FASDs?

Children with FASDs might have the following characteristics or exhibit the following behaviors:

- Small size for gestational age or small stature in relation to peers
- Facial abnormalities such as small eye openings
- Poor coordination
- Hyperactive behavior
- Learning disabilities
- Developmental disabilities (e.g., speech and language delays)
- Intellectual disability or low IQ
- Problems with daily living

Poor reasoning and judgment skills  
 Sleep and sucking disturbances in infancy

A child who is diagnosed early in life can be placed in appropriate educational classes and given access to social services that can help the child and his or her family. Children with FASDs who receive special education are more likely to achieve their developmental and educational potential. In addition, children with FASDs need a loving, nurturing, and stable home life to avoid disruptions, transient lifestyles, or harmful relationships. Children with FASDs who live in abusive or unstable homes or who become involved in youth violence are much more likely than those who do not have such negative experiences to develop secondary conditions.

Date: May 2, 2006

Content source: National Center on Birth Defects and Developmental Disabilities

### Developmental Delay in Children

In the U.S., nearly seventeen percent (17%) of all children experience some form of developmental delay or behavioral disability. Recognizing a disability early such as autism is key for parents and healthcare providers.

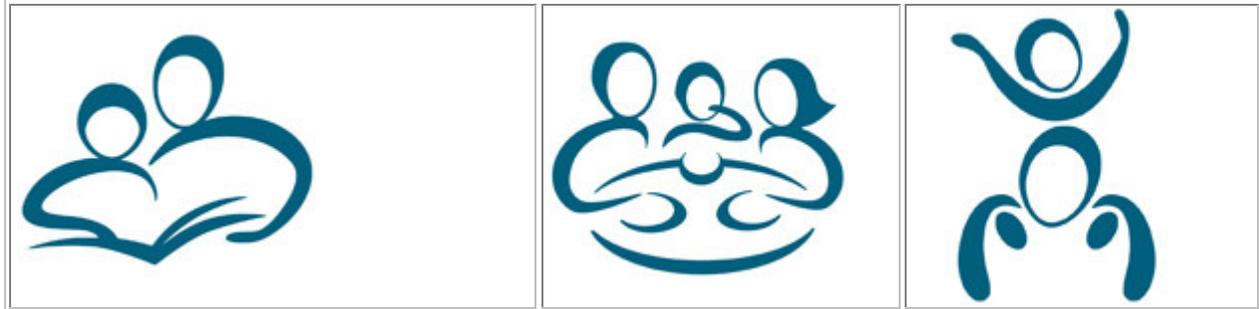
#### What is Developmental Delay?

**Developmental Delay** is when a child does not reach medically recognized developmental milestones (see the chart below) at the expected times. Development can be delayed in one or more areas—for example: motor, language, social, or thinking skills.

#### Developmental Milestones

		
<p><b>3 months</b></p>	<p><b>6 months</b></p>	<p><b>12 months</b></p>
<ul style="list-style-type: none"> <li>• Turn their heads toward bright colors and lights</li> <li>• Recognize bottle or breast</li> <li>• Respond to their mother's voice</li> <li>• Make cooing sounds</li> <li>• Bring their hands</li> </ul>	<ul style="list-style-type: none"> <li>• Follow moving objects with their eyes</li> <li>• Turn toward the source of normal sound</li> <li>• Reach for objects and pick them up</li> </ul>	<ul style="list-style-type: none"> <li>• Get to a sitting position</li> <li>• Stand briefly without support</li> <li>• Crawl</li> <li>• Imitate adults using a cup or telephone</li> <li>• Play peek-a-boo and</li> </ul>

<p>together</p> <ul style="list-style-type: none"> <li>• Wiggle and kick with arms and legs</li> <li>• Lift head when on stomach</li> <li>• Become quiet in response to sound, especially to speech</li> </ul>	<ul style="list-style-type: none"> <li>• Play with their toes</li> <li>• Help hold the bottle during feeding</li> <li>• Recognize familiar faces</li> <li>• Imitate speech sounds</li> <li>• Roll over</li> </ul>	<p>patty cake</p> <ul style="list-style-type: none"> <li>• Wave bye-bye</li> <li>• Put objects in a container</li> <li>• Make "ma-ma" or "da-da" sounds</li> </ul>
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<b>18 months</b>	<b>24 months</b>	<b>36 months</b>
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<ul style="list-style-type: none"> <li>• Like to push and pull objects</li> <li>• Say at least six words</li> <li>• Follow simple directions</li> <li>• Pull off shoes, socks, and mittens</li> <li>• Can point to a picture that you name in a book</li> <li>• Feed themselves</li> <li>• Make marks on paper with crayons</li> <li>• Walk without help</li> <li>• Walk backwards</li> <li>• Point, make sounds and try to use words to ask for things</li> </ul> <p>Source: <a href="http://www.mychildwithoutlimits.org">www.mychildwithoutlimits.org</a></p>	<ul style="list-style-type: none"> <li>• Use two-to-three-word sentences</li> <li>• Say about 50 words</li> <li>• Recognize familiar pictures</li> <li>• Kick a ball forward</li> <li>• Feed themselves with a spoon</li> <li>• Demand a lot of your attention</li> <li>• Turn two or three pages together</li> <li>• Identify hair, eyes, ears, and nose by pointing</li> <li>• Show affection</li> </ul>	<ul style="list-style-type: none"> <li>• Throw a ball overhand</li> <li>• Ride a tricycle</li> <li>• Put on their shoes</li> <li>• Open the door</li> <li>• Turn one page at a time</li> <li>• Play with other children for a few minutes</li> <li>• Repeat common rhymes</li> <li>• Use three -to-five-word sentences</li> <li>• Name at least one color correctly</li> </ul>
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*The first three years of a child's life are an amazing time of development...and what happens during those years stays with a child for a lifetime. The sooner children who are developmentally delayed get [early intervention](#), the better their prognosis for improvement and progress will be.*

A developmental delay occurs when a child reaches a milestone at an age later than the average developmental rate across the general population. By eight months old, the majority of children turn their heads upon hearing their name, smile back when someone smiles, and enjoy playing games like peek-a-boo. At eighteen month-old, children can engage in simple pretend play, point to an interesting object, or speak single words without prompting. By their second birthday, many children speak in two-to-four-word phrases. Most of the time, a developmental problem is not something children grow out of on their own. However, with early help, these children can often reach their full potential.

All children develop at their own pace and many reach particular milestones slightly later or earlier than their peers.

Keeping track of how children play, learn, speak, and act is really important.

## **Early Intervention and Special Education**

### **What is early intervention?**

Early Intervention (EI) is the offering of programs and services to children who may be experiencing developmental delays before the age of three. The early intervention is of the utmost importance to children and families and may help children meet early childhood developmental milestones. Early intervention programs offer many different services and will help to set up individualized programs for the child and his/her family. Early Intervention programs may include one or all of the following services: assessment by a qualified therapeutic team to determine level of services, individual therapeutic services such as speech, physical, and occupational therapies, group therapies with qualified EI staff helping to socialize children who are experiencing developmental delays, individual therapies with a developmental therapist. Early Intervention services end at age three.

**For children with developmental delay, it is most important to start treatment as early as possible, and make sure it involves lots of one-on-one interaction with the child.**

### **What is special education?**

**Special education** means "educational programming designed specifically for the person." It helps children do better in school. School-aged children who qualify for special education will have an [Individualized Education Program](#) (IEP) designed just for them.

**What happens when the child grows up and becomes an adult?**

As a child gets closer to adulthood, he/she will need an [IEP transition plan](#). Transition planning begins at age 14. It is part of the IEP every year after that. At age 16, planning will begin for how the child will transition from school to the community. The goal is for the child to become as independent as possible. [The National Center on Secondary Education and Transition](#) (NCSET) coordinates national resources, offers technical assistance, and provides information on secondary education and transition for youth with disabilities. Their website provides a wealth of further information. <http://www.ncset.org/default.asp>

**Individualized Education Program (IEP) for Children**

Children with developmental disabilities are entitled to an IEP. School personnel and the child's parents must develop the IEP before the beginning of the child's school year and then implement the plan...IEPs are an agreement between the school and the parents that specifies how the student will be educated.

- Evaluation is the first step in the IEP process. All the IEP team's decisions must be based on evaluation data. The child must be evaluated in all areas of suspected disability.
- Curriculum is the next step. Federal law requires that the IEP have a statement describing how the child's progress will be measured. For example, "According to the Woodcock-Johnson Reading Mastery Test, Johnny is able to comprehend reading material on a 4th grade level with 90% accuracy." Formal assessment is just one method. Daily grades and teacher/parent reports can also be used.
- Placement is the last step of the IEP process. There must be a statement that includes how the child will be educated and participate with other children with disabilities and without disabilities. If the child will not participate with his/her non-disabled peers in the regular class and activities, the team must note why in a written explanation.
- Placement decisions are based on the child's IEP goals and objectives. The child is placed in more restrictive settings only if the goals and objectives can not be met in the general classroom with supplementary aids and supports. The IEP team must make a good faith effort to provide appropriate support before removing the child to a more restrictive setting.

Source: *Educational Rights Information & Consulting Center*  
<http://www.tsbvi.edu/Outreach/seehear/winter02/iep.htm>

**Individualized Family Service Plan (IFSP)**

An ISFP is a written early intervention plan developed by a multidisciplinary team that includes the family as a primary participant. The IFSP describes the child's developmental levels in all areas; the family's resources, priorities, and concerns relating to enhancing the development of their child; and the services to be received, including the frequency, intensity, and method of delivering services. In addition, the IFSP must contain a statement of the natural environments in which early intervention services will occur. Projected dates for service initiation and duration must be given, and a service coordinator from a profession most relevant to the child or family's needs must be named. The IFSP must be reviewed at least every six months and updated following annual assessments. It can be updated sooner if the child's needs change.

Source: <http://ericec.org/digests/e605.html>

**DCFS – Child Abuse and Neglect Information**

***Professionals Who Work With Children Need to Know:***

- Who must report suspected abuse or neglect of children?
- What happens when a report of child abuse or neglect is made?
- Why are some cases accepted for investigation while others are not?
- What are the legal definitions of abuse and neglect and how are they interpreted?
- What legal protections are afforded mandated reporters?
- What are the possible penalties for failure to report?
- What happens after a report is accepted?

**DCFS Definitions**

**Physical Abuse** as defined by **(Abused and Neglected Child Reporting Act) ANCRA, (Sec.3)** occurs when a parent or a person responsible for the child's welfare:

- "inflicts, causes to be inflicted, or allows to be inflicted upon such child physical injury, by other than accidental means, which causes death, disfigurement, impairment of physical or emotional health, or loss or impairment of any bodily function". Such common injuries include bruises, human bites, bone fractures, and burns.
- "creates a substantial risk of physical injury" likely to have physical impacts.

**Sexual Abuse** - occurs when a person responsible for the child's welfare commits any of the following acts:

- sexually transmitted diseases are by DCFS definition "diseases which were acquired originally as a result of sexual penetration or conduct with an individual who was afflicted"
- sexual penetration includes any contact between the sex organ of one person and the sex organ, mouth, or anus of another person. Typical acts include vaginal, oral and anal sex.



**Sexual Exploitation- Children**

- **sexual exploitation** is defined by DCFS as "sexual use of a child for sexual arousal, gratification, advantage, or profit". This includes such acts as explicit verbal enticements, child pornography, self masturbation in the child's presence, and forcing a child to watch sex acts.
- **sexual molestation** is defined by DCFS as "sexual conduct with a child when such contact, touching, or interaction is used for arousal or gratification of sexual needs or desires". Examples include fondling a child or having the child touch the perpetrator sexually. (DCFS Procedures 300.Appendix B)

**Neglect** occurs when a person responsible for the child deprives or fails to provide the child with adequate food, clothing, shelter, or needed medical treatment. Neglect is also alleged when an adult provides inadequate supervision of a child. This can occur when children are left either unsupervised or in the care of someone unable to supervise due to his/her condition. Children can suffer injuries that are the result of "blatant disregard" and are considered neglect.

According to DCFS, "Blatant disregard is a situation in which the risk of harm to a child is so imminent and apparent that it is unlikely that any parent or caretaker would expose the child to such without taking precautionary measures to protect the child."(DCFS Proc.300 App.B)

The definitions in ANCRA are not perfectly clear in helping mandated reporters (or DCFS investigators later) in distinguishing between inappropriate/undesirable parenting and those acts which constitute abuse and neglect. It is clear that there are many points at which judgments must be made.

- What is excessive corporal punishment?
- At what age is it safe to leave children alone?
- At what point does a dirty house become a health and safety concern?
- How do you distinguish poverty from neglect?
- A question to ask yourself is "Has the child been harmed or been at substantial risk of harm?"

This helps focus the issue and moves away from value judgments and attitudes about lifestyles.

### **Checklist for Mandated Reporters**

**Mandated reporters** are professionals who may work with children or people with developmental disabilities in the course of their professional duties.

There are seven groups of mandated reporters as defined in the ANCRA, Sec.4:

- 1) **Medical Personnel:** for example, physician, dentist, LPN, RN, medical social worker, emergency medical technician, nurse practitioner, chiropractor, hospital administrator.
- 2) **School Personnel:** includes administrators and certified and non-certified staff such as superintendent, teacher, principal, school counselor, school nurse, school social worker, assistant principal, teacher's aide, truant officer, school psychologist, and secretary.

If an allegation of abuse is raised to a school board member, the school board as a governing body or the individual member has the authority to direct the superintendent of the school district, or other equivalent school administrator, to report the abuse as required by the Abused and Neglected Child Reporting Act.

- 3) **Social Service/Mental Health Personnel:** for example, mental health personnel, social workers, psychologists, domestic violence personnel, substance abuse treatment personnel, staff of state agencies dealing with children such as Department of Human Services, Department of Public Aid, Department of Public Health, Department of Corrections, and Department of Children and Family Services.
  - 4) **Law Enforcement Personnel:** for example, employees of the court, parole/probation officer, emergency services staff, police, states attorney and staff, juvenile officer.
- 5) Coroner/Medical Examiner Personnel**
- 6) **Child Care Personnel:** includes all staff at overnight, day care, pre-school or nursery school facilities, recreational program personnel, foster parents.
  - 7) **Members of the Clergy:** includes any member of the clergy that has reasonable cause to believe that a child known to him or her in a professional capacity may be an abused child.

Mandated reporters are **required** to report suspected child maltreatment immediately when they have "**reasonable cause to believe**" that a child known to them in their professional or official capacity may be an abused or neglected child". (ANCRA Sec.4)

### **DCFS Reporting**

**If in Illinois, call 1-800-252-2873 (1-800-25ABUSE) or 1-800-358-5177 (TTY) If outside Illinois, call (217) 524-2606**

**CAUTION: DO NOT use e-mail to report child abuse or neglect. It causes delays and confidentiality may not be ensured.**

You must report to the local police allegations of anything illegal. You should always consider calling the police - especially in emergencies where life or safety is at risk, for crimes or when someone is threatened with harm. To ensure an investigation by OIG, you must also call OIG's Abuse and Neglect Hotline at **1-800-368-1463**.

## Child Abuse Reporting

You should call the child abuse hotline whenever you believe that a person who is caring for the child, who lives with the child, or who works with or around children has caused injury or harm or put the child at risk of physical injury as defined in the Abused and Neglected Child Reporting Act. Some examples include:

- If you see someone hitting a child with an object.
- If you see marks on a child's body that do not appear to have been caused by accident.
- If a child tells you that he or she has been harmed by someone.
- If a child appears to be undernourished, is dressed inappropriately for the weather, or is young and has been left alone.

These are a few situations when you should call the hotline. Use your own judgment and call the hotline whenever you think a child has been abused or neglected.

## When Should I Not Call the Hotline?

Some situations do not require calling the hotline. Use good judgment. Call only when you think a child has been or will be injured as described above. Some examples of when you should **not** call the hotline include:

- Situations where a child is causing a problem that concerns you, but the problem is not related to abuse or neglect. In some cases you may wish to call law enforcement or talk to the child's parents or relatives.
- Domestic situations where family stress is evident, but the child has not been abused or at risk of abuse. Community service agencies are often available to help.
- If you're seeking information about DCFS or its programs, our Office of Communications is available to answer questions. Call (217)785-1700, or you may call your local DCFS office.

## What Should I Report?

Hotline staffs are social workers with special training in determining what constitutes child abuse and neglect under Illinois law. Details are important. Ideally, you should be able to tell the Hotline worker:

- The child's name, address and age.
- The nature of suspected abuse or neglect, including when and where it occurred.
- The names of suspected perpetrators and their relationship to the child (parent, teacher, etc.).
- Any other information you think may help.

## **What Happens When I Call the Hotline?**

When you call, a hotline social worker will listen to what you wish to report. The worker will then ask questions to help gather enough information to determine whether to take a formal report. If there is not enough information to make a report, the worker will tell you so and answer any questions you may have.

If a formal report is taken, a child protection investigator will begin the investigation within 24 hours -- much sooner if the child is considered in immediate risk of harm.

## **How am I Protected?**

People who report alleged child abuse or neglect in good faith cannot be held liable for damages under criminal or civil law. In addition, their names are not given to the person they name as the abuser or to anyone else unless ordered by a hearing officer or judge. Members of the general public may make reports without giving their names.

## **Should I call the Police?**

Always call the child abuse hotline. However, you should also consider calling the police -- especially in emergencies or when the child has been injured.

## **How Else Can I Help?**

The Illinois income tax check-off program enables anyone to donate to the Child Abuse Prevention Fund when they file their state income tax returns. The money is used to support community-based family education programs designed to help parents improve their parenting skills and to help them learn how to cope with family life.

DCFS also offers a wide variety of volunteer programs for people wanting to serve their communities. Call your local DCFS office for details, or write to the Office of Volunteer Services, 406 E. Monroe, Springfield, IL 62701.

## **Who are Mandated Reporters?**

Members of the general public may report suspected child abuse and neglect if they choose. However, state law mandates that workers in certain professions must make reports if they have reasonable cause to suspect abuse or neglect.

Mandated reporters who make good faith reports have the same immunity from liability under the law as non-mandated reporters.

## **How Should Mandated Reporters Make Reports?**

Call the child abuse hotline as soon as possible. Then you must send written confirmation to the appropriate DCFS field office within 48 hours. The Department will provide a form to use when sending this confirmation. If you suspect a child's death may have been caused by abuse or neglect, you must also call your county's coroner or medical examiner.

### **NOTICE**

Any person who knowingly transmits a false report to the Department commits the offense of disorderly conduct under subsection (a)(7) of Section 26-1 of the Criminal Code of 1961. A first violation of this subsection is a Class A misdemeanor, punishable by a term of imprisonment for up to one year, or by a fine not to exceed \$1,000, or by both such term and fine. A second or subsequent violation is a Class 4 felony.

Each allegation of abuse and neglect must be reported to the OIG hotline (800-368-1463) within 4 hours of the initial discovery.

Since June 13, 2006, intentionally reporting an allegation late— or not reporting it at all— is a Class A misdemeanor. If you are convicted, it is punishable by: up to one year in jail and/or a \$2,500 fine.

### **Guidelines for Calling the Child Abuse Hotline Illinois Child Abuse Hotline**

**1-800-25-ABUSE or 1-800-252-2873**  
**1-800-358-5117 (TTY)**  
**217-524-2606 if calling from outside Illinois**

The Hotline operates 24 hours per day, 365 days a year. Reporters should be prepared to provide phone numbers where they may be reached throughout the day in case the Hotline must call back for more information.

Mandated reporters and other persons should call the Hotline when they have reasonable cause to suspect that a child has been abused or neglected. The Hotline worker will determine if the information given by the reporter meets the legal requirements to initiate an investigation.

### **Criteria needed for a child abuse or neglect investigation**

- The alleged victim is a child under the age of 18.

- The alleged perpetrator is a parent, guardian, foster parent, relative caregiver, paramour, any individual residing in the same home, any person responsible for the child's welfare at the time of the alleged abuse or neglect, or any person who came to know the child through an official capacity or position of trust (for example: health care professionals, educational personnel, recreational supervisors, members of the clergy, volunteers or support personnel) in settings where children may be subject to abuse and neglect.
- There is a specific incident of abuse or neglect or a specific set of circumstances involving suspected abuse or neglect.
- There is demonstrated harm to the child or a substantial risk of physical or sexual injury to the child.

**Information the reporter should have ready to give to the Hotline**

- Names, birth dates (or approximate ages), races, genders, etc. for all adult and child subjects.
- Addresses for all victims and perpetrators, including current location.
- Information about the siblings or other family members, if available.
- Specific information about the abusive incident or the circumstances contributing to risk of harm—for example, when the incident occurred, the extent of the injuries, how the child says it happened, and any other pertinent information.

**If this information is not readily available, the reporter should not delay a call to the hotline.**

## Separation Anxiety and Children With Developmental Disabilities

DSPs should know that separation anxiety can occur with children with DD. Separation anxiety is the response to the threat of loss or fear of abandonment of a loved one. Children and adolescents affected by Separation Anxiety Disorder become severely distressed when separated from their familiar surroundings and caregivers. The very thought of being separated from family members may cause anxiety feelings, and actual separation leads to pronounced distress and agitation. This distress is persistent and frequent, and interferes with the child's ability to engage in normal age-appropriate activities that require temporary separation from caregivers (e.g., attending *school and community-based activities*). This can arouse anger, especially in older children and adolescents. Children may also become preoccupied by a fear that accidents or illnesses will harm caregivers or themselves during the period of separation.

Examples of separation anxiety:

- Clingy behavior; children may shadow caregivers throughout their day rather than play independently.
- Difficulty with separating from caregivers at bedtime (e.g., children may want a caregiver to stay with them until they fall asleep).
- Physical symptoms (e.g., stomachache, headache, or nausea) when separated or when worrying about being separated from caregivers.

Separation anxiety can put significant stress on the child and the caregiver. Separation anxiety can vary depending on the child's disability. A child with motor deficits may not respond to physical comforting. Children with impaired hearing may be at increased risk for disruption of the attachment process. There are therapies and medications that can help the symptoms of anxiety disorder. DSPs should advise their agency's QMRP and the child's parent(s) or guardian when children in their care exhibit symptoms of separation anxiety.

Source: Concise Encyclopedia of Special Education and [info@mhmrcv.org](mailto:info@mhmrcv.org)

## Basic Principles of Communicating with Children

These principles can help you develop a good relationship with children you support.

- Let the child know you are interested and involved and will help when needed.
- Turn off the television or put down the newspaper when a child wants to talk.
- Avoid taking a telephone call when the child has something important to tell you.
- Unless other people are specifically meant to be included, hold conversations in privacy. The best communication between you and the child will occur when others are not around.
- Embarrassing the child or putting him or her on the spot in front of others will lead only to resentment and hostility, not good communication.
- Don't tower over a child. Physically get down to the child's level then talk.
- If you are very angry about a behavior or an incident, don't attempt communication until you regain your cool. You cannot be objective until then. It is better to stop, settle down, and talk to the child later.
- If you are very tired, you will have to make an extra effort to be an active listener. Genuine active listening is hard work and is very difficult when your mind and body are already tired.
- Listen carefully and politely. Don't interrupt the child when he is trying to tell his story. Be as courteous to your child as you would be to your best friend.
- Don't be a wipe-out artist, unraveling minor threads of a story and never allowing the child's own theme to develop. This is the parent who reacts to the incidentals of a message while the main idea is lost: i.e., the child starts to tell about what happened and the parent says, "I don't care what they are doing, but you had better not be involved in anything like that."
- Don't ask *why*, but do ask *what* happened.
- If you have knowledge of the situation, confront the child with the information that you know or have been told.
- Keep adult talking ("You'll talk when I'm finished." "I know what's best for you." "Just do what I say and that will solve the problem"), preaching and moralizing to a minimum because they are not helpful in getting communication open and keeping it open.
- Don't use put-down words or statements: dumb, stupid, lazy: "Stupid, that makes no sense at all" or "What do you know, you're just a child."
- Assist the child in planning some specific steps to the solution.
- Show you accept the child himself, regardless of what he has or has not done.
- Reinforce the child for keeping communication open. Do this by accepting him and praising his efforts to communicate.

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## How Children Grieve

Grieving the loss of a loved one is difficult, especially for a child. When a child loses a loved one to death or incarceration, the loss can have a profound effect on the rest of his or her life.

Emotional, psychological and physical trauma often comes with loss challenge children's well-being and school performance. Grieving children are likely to feel different, and very alone.



While concealing deep emotional pain, fear and loss of concentration, children are in the pressure cooker of expectations to grow emotionally and academically. They say that seeing friends with parents and parent/child school activities are daily reminders of their own loss.

Children express grief in a different way than adults. They tend to move in and out of intense feelings, rather than sustaining high levels of one emotion for long periods of time. When adults see a grieving child playing or laughing, they may mistakenly believe that the child is "over it". This perception may influence how much grief support a child receives.

## **Navigating Children's Grief: How to Help Following a Death** **Age Concepts and Beliefs Difficult Emotions Possible Behaviors How to Help**

### **Birth–2 years**

- No understanding of death
- Child does not have words for feelings
- Aware of the absence of the loved one
- Notices changes in routine
- Notices changes in family emotions
- Longing
- Misses contact, sounds, smell and sight of loved one
- Fears of being abandoned
- Anxiety
- Crying
- Sickliness
- Indigestion
- Thrashing
- Rocking
- Throwing
- Sucking, biting
- Sleeplessness
- Physical contact, cuddling and reassurance
- Maintain routines

- Meet immediate physical needs
- Include the child in the mourning process when possible
- Be gentle & patient

### **3-5 years**

- No understanding of permanence of death
- To be dead is to be sleeping or on a trip
- May wonder what deceased is doing
- Understands biological processes have stopped, but see it as temporary and reversible
- May wonder what will happen if the other parent dies
- Magical thinking and fantasies, often worse than realities
- Fear
- Sadness
- Insecurity
- Confusion
- Anger
- Irritable
- Agitated
- Worried
- Guilty
- Regressive behaviors
- Repetitive questions
- Withdrawn
- Plays out scenes of death, change and feelings
- Interested in dead things
- Acts as if death never happened
- Intense dreams
- Physical complaints
- Crying
- Fighting
- Allow the child to regress
- Give physical contact
- Encourage children to play and have fun
- Allow safe ways to express feeling
- Give simple & truthful answers to questions
- Maintain structure and routines
- Answer repetitive questions
- Let the child cry
- Talk (reflective listening)
- Include child in family rituals and mourning

### **6-9 years**

- Understands that death is final
- Interested in the biology of death
- Death associated with bodily harm, mutilation & decay
- His or her thoughts, actions or words caused the death
- Death is punishment
- Forming spiritual concepts
- Who will care for me if my caregiver dies
- Thinks about life's milestones without the deceased (graduation, marriage, etc.)
- Sad
- Anger
- Lonely
- Withdrawn
- Worried
- Anxious
- Irritable
- Confusion
- Guilty
- Fear
- Regressive behaviors
- Specific questioning –looking for details
- Acts as if the death never happened
- Hides feelings
- Withdrawal
- Nightmares / sleep disturbances
- Concentration difficulties
- Declining or greatly improved grades
- Aggressive acting out
- Protective of surviving loved ones
- Allow need to regress
- Give physical contact
- Have intentional times together
- Answer questions truthfully
- Watch for confusion
- Allow expression of feelings through verbal & physical outlets
- Encourage drawing, reading, playing, art, music, dance, acting, sports
- Let child choose how to be involved in the death & mourning
- Find peer support for the child
- Work with school to tailor workload

### 9-12 years

- Understands the finality of death
- Denial
- His/her words, thoughts or actions caused the death
- Thinks about life's milestones without the deceased (graduation, marriage, etc.)
- High death awareness (death may happen again)
- What if my caregiver dies?
- Formulating spiritual concepts
- Emotional turmoil heightened by physical changes
- Shock
- Sad
- Anger
- Confused
- Lonely
- Vulnerable
- Fear
- Worried
- Guilty
- Isolated
- Abandoned
- Anxious
- Regressive behavior & fluctuating moods
- Hides feelings
- Acts like death never happened
- Aggressive acting out
- Withdrawal
- Nightmares & sleep disturbances
- Concentration difficulties
- Changes in grades
- Talks about physical aspects of illness or death
- Allow regressive behavior & offer comfort
- Expect & accept mood swings
- Encourage expression of feelings through writing, art, music, sports, etc.
- Find peer support groups
- Be available to listen and talk
- Answer questions truthfully
- Offer physical contact
- Give choices about involvement in death & mourning 12 years and up (teenagers)
- Understands the finality & universality of death
- Denial
- His/her words, thoughts or actions caused the death
- Thinks about life's milestones without the deceased (graduation, marriage, etc.)
- High death awareness (death may happen again)
- May sense own impending death
- I need to be in control of feelings. If I show my feelings, I will be weak

- Internal conflict about dependence & desiring independence
- May utilize spiritual concepts to cope
- Highly self-conscious about being different due to grief
- Shock
- Sad
- Anger
- Confused
- Lonely
- Vulnerable
- Fear
- Worried
- Guilty
- Isolated
- Abandoned
- Anxious
- Occasional regressive behavior
- Mood swings
- Hides feelings
- Acts like death never happened
- Acts out role confusion
- Aggressive acting out
- Withdrawal
- Nightmares & sleep disturbances
- Concentration difficulties
- Changes in grades
- Impulsive & high risk behavior
- Changes in peer groups
- Fighting, screaming, arguing
- Changes in eating patterns
- Allow regressive behavior & offer comfort
- Expect & accept mood swings
- Allow hidden feelings unless there is risk of harm
- Encourage expression of feelings through writing, art, music, sports, etc.
- Support relationships with understanding adults
- Be available to listen and talk
- Answer questions truthfully
- Share your grief
- Watch for high risk behavior
- Find peer support groups
- Offer physical contact
- Allow choices about involvement in death & mourning

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## **GUARDIANSHIP VS. PARENTAL RIGHTS**

Direct care staff may provide Medicaid-Waiver funded services to children who live with relatives or guardians instead of their natural parents. Or, children may be living with only one of their parents. Guardians or custodial parents of children are responsible for the day-to-day care of child. These living arrangements might be temporary or permanent. Some of the most common reasons for this are divorce, a parent is becomes ill or a parent cannot care for the children because of child abuse or neglect, addiction, or other problems. Biological parents, or non-custodial parents can have rights to visit with the child and a right to ask the court to terminate the guardianship. It is possible that conflicts might arise regarding the child's care in these situations. Direct care staff should immediately contact their agency supervisor and the agency QMRP for advice if the custodial guardian/parent and the non-custodial parent(s) disagree and give the DSP conflicting instructions concerning the child's care.

### **TYPES OF GUARDIANSHIPS FOR CHILDREN UNDER 18**

#### **Juvenile Court Guardianship**

DCFS investigates claims of child abuse or neglect made to its hotline (1-800-25-ABUSE). Some hotline calls result in Juvenile Court cases and children are removed from their parents' care. When children are removed, the court can place the child in DCFS Guardianship or with a relative in Private Guardianship.

#### **DCFS Guardianship**

- For a DCFS guardianship, the court names a DCFS official as the guardian for the child. DCFS then has the right to place the child in the home of a foster parent or relative caretaker. The child can be placed directly by DCFS or through a private agency.

## Children's Service Planning

In addition to the services the diagnostician prescribes or recommends for the child, parents and the caregivers can search to locate the best mix of resources and services. Many services and resources will be **community-based**. Remember, just because a child has some developmental disabilities, they are also gifted with many **abilities** too. The key to success is finding the right blend of assistance and opportunities that will allow the child to continue to grow and meet their potential.



This “blend” will change as the child develops and it is greatly dependent on the following factors:

- Diagnosis—the type of Developmental Disability will influence
- Geography— where you live impacts what services are available
- Age— some services are only available to certain age groups.

Obviously, there are different services in different areas of the state. The trick is to find ones that the child is eligible to use.

- Understand the disability
- Identify the strengths of the child
- Set realistic expectations that allow the child to succeed
- Convey expectations in a simple language that the child understands
- Recognize expectations must change to meet the changing needs of the child and family
- Simplify the child's environment
- Establish and maintain routines
- Understand that inappropriate behavior may stem from difficulty in communicating

Some children may need help with daily living activities. Strategies to help the family allow the child to learn daily living activities include:

- Ask child's teacher to help the child learn self-care
- Get specific self-help skills written into the IEP
- Work with families and professionals as a team on daily living skills
- Break tasks down into manageable steps
- Decide what steps of any activity the child is expected to do
- Help as needed
- Incorporate activities of daily living into family's routine
- Set expectations for both work and play that the whole family shares

## **What community services are open to children and youth with developmental disabilities?**

- All community-based, publicly funded services and activities are open to children and youth with developmental disabilities.
- Children and youth with developmental disabilities can NOT be excluded from publicly funded services or activities.
- The Americans with Disabilities Act (ADA) prohibits discrimination in the provision of publicly funded services on the basis of disability or disability label.
- Children and youth with developmental disabilities may need specialized supports in order to participate in community-based activities.
- Anyone can contact national organizations or local chapters about specific disabilities.
- Anyone can contact the local Department of Human Services Family Community Resource Centers for screening and referral.
- Talk to the special education staff at the local schools (both public and private) and preschool and early intervention program staff;
- Contact social service departments at children's hospitals;
- Contact vocational rehabilitation counselors and the staff at independent living centers or group homes.
- Look in the phone book under either the specific disability or in the yellow pages under Disability Services.
- Parents and other caregivers can ask DCFS or other child welfare workers or school staff for a list of community programs and activities.
- Anyone can contact local Chamber of Commerce offices or the Office of Mental Health/Developmental Disabilities for materials on services and activities in the area.
- Visit any programs to see how they are operated in order to prepare to provide appropriate support for a child with developmental disabilities who wants to access them.
- Talk with parents, foster parents and other caregivers to find out what is available.
- Be sure to look at ALL children or young adult programs, not just those designed specifically for children with developmental disabilities.

## **How can parent and family support groups and networks help in accessing services?**

Parents and support groups have years of knowledge to share. They have experience in accessing local services. Help families access these support groups.

**How can children with Developmental Disabilities access services that are not specifically for children with DD?**

- Caseworkers and families can enroll children and young adults in community based programs (based on the interests of the child or young adult.)
- When enrolling, case managers and families can discuss the need for support for youth with developmental disabilities in these settings.
- Teams can provide a variety of supports including transportation, communication support, interpreters, interpersonal support, and accessibility supports.
- Over time, supports may begin to be provided by the service providers themselves.

**Some community-based activities and programs are:**

- Gymnastics
- Scouting
- Before and after school programs
- Art and craft programs
- Dance
- Church related programs
- Cultural center activities
- YMCA, YWCA
- Therapeutic horseback riding
- Working with animals
- Service club activities (Lions, Kiwanis, etc.)

**Be sure to look at ALL children or young adult programs, not just those designed specifically for children with developmental disabilities.**

<b>PROFESSIONALS WHO PROVIDE SERVICES TO CHILDREN WITH DISABILITIES</b>		
<b>DISCIPLINE</b>	<b>PRIMARY FOCUS FOR ASSESSMENT</b>	<b>PRIMARY AREA OF INTERVENTION</b>
Assistive Technology Specialist	Need for assistive technology such as computers, communication boards, word processors	Use of technology as an aid to improve outcome
Audiologist	Hearing	Hearing and ear functioning
Infant Specialist	Overall interaction, play, cognitive development, social skills	All areas of functioning in consultation with other specialists
Nutritionist	Feeding skills, oral-motor development, diet analysis, growth	Feeding, oral-motor skill, nutrition education
Occupational Therapist	Fine motor development: hand use, oral motor development, feeding	Feeding, reaching and grasping, sensory-motor development, perceptual-motor skills
Physical Therapist	Gross motor development: sitting, crawling, standing, walking	Development of locomotion, use of adaptive equipment
Psychologist	Interaction, play, cognitive development, social skills, behavior management, emotional support	Family adjustment, behavior management
Special Educator	Development skill acquisition, school achievement	School achievement
Speech Pathologist	Expressive and receptive language, oral motor development, feeding	Communication skills, alternative communication systems

## Resources

### WEB RESOURCES

- ▶ SIU School of Medicine Library  
<http://www.siumed.edu/lib/>
  
- ▶ Illinois Early Childhood Intervention Clearinghouse - Request info, video tapes, books, resources can be sent to you on any DD  
Phone: (217) 785-1364 or toll free (800) 852-4302  
<http://www.eiclearinghouse.org/>
  
- ▶ LifeSpan  
<http://www.illinoislifespan.org/>
  
- ▶ Advocacy Agencies for each diagnosis:
- ▶ Institute on Disability and Human Development  
<http://www.idhd.org/>
  
- ▶ Family Resource Coalition of America (FRCA)  
20 North Wacker Drive, Suite 1100  
Chicago, IL 60606  
Phone: (312) 338-0900  
Fax: (312) 338-1522  
[www.f-r-c.org/](http://www.f-r-c.org/)
  
- ▶ Family Support Network  
<http://www.familysupportnetwork.org/>
  
- ▶ The Autism Program – Your Illinois Resource  
<http://www.theautismprogram.org/>